OFFICIAL REPORT
AITHISG OIFIGEIL

Health and Sport Committee

Tuesday 6 November 2018

Session 5

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 6 November 2018

CONTENTS

HEALTH AND SPORT COMMITTEE
28th Meeting 2018, Session 5

CONVENER

*Lewis Macdonald (North East Scotland) (Lab)

DEPUTY CONVENER

*Emma Harper (South Scotland) (SNP)

COMMITTEE MEMBERS

*Miles Briggs (Lothian) (Con)
*Keith Brown (Clackmannanshire and Dunblane) (SNP)
*Alex Cole-Hamilton (Edinburgh Western) (LD)
*David Stewart (Highlands and Islands) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Sandra White (Glasgow Kelvin) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Shaben Begum (Scottish Independent Advocacy Alliance)
Harpreet Brrang (Children's Liver Disease Foundation)
Joe FitzPatrick (Minister for Public Health, Sport and Wellbeing)
Gillian Hollis
Fiona Loud (Kidney Care UK)
Dr Gordon Macdonald (Christian Action Research and Education)
Elspeth Macdonald (Food Standards Scotland)
David McColgan (British Heart Foundation Scotland)
Neel Mojee (Scottish Government)

CLERK TO THE COMMITTEE

David Cullum

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 6 November 2018

[The Convener opened the meeting at 09:35]

Decision on Taking Business in Private

The Convener (Lewis Macdonald): Good morning and welcome to the 28th meeting of the Health and Sport Committee in 2018. I ask everyone to ensure that their mobile phones are on silent, and although you may use mobile devices for social media purposes, I ask members of the public please not to take photographs or record proceedings.

Item 1 is for the committee to decide whether to take in private item 6 and all future consideration of evidence received on proposals by the Scottish Government to consent to the United Kingdom Government legislating using the powers under the European Union (Withdrawal) Act 2018 in relation to UK statutory instrument proposals. Do members agree?

Members *indicated agreement.*

European Union (Withdrawal) Act 2018

Human Tissue (Quality and Safety for Human Application) (Amendment) (EU Exit) Regulations

Quality and Safety of Organs Intended for Transplantation (Amendment) (EU Exit) Regulations

Blood Safety and Quality (Amendment) (EU Exit) Regulations

09:35

The Convener: Item 2 is consideration of a proposal by the Scottish Government to consent to the UK Government using powers under the 2018 act in relation to three UK statutory instrument proposals.

At our meeting on 23 October, we agreed that we would write to the UK Government to request confirmation that the Scottish Government would receive final versions of each of the statutory instruments and confirmation of when they would be issued.

We have received a response from Jackie Doyle-Price, who is Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention in the UK Government Department of Health and Social Care. She said:

"The Scottish Government received copies of the updated draft instruments for organs and tissues and cells on 22 October."

She went on to say that

"Final checks are currently being undertaken",

and indicated that although there might be further "technical modifications" to the drafts, no policy changes are expected. The letter advised that the latest version of the statutory instruments would be sent to the Scottish Government by 2 November.

We have since received a response from Joe FitzPatrick, the Minister for Public Health, Sport and Wellbeing, copies of which members should have access to, in which Mr FitzPatrick says that although the drafts of all three statutory instruments are still being finalised by the Department of Health and Social Care in advance of being laid, the Scottish Government has now seen final drafts of all three SIs and is satisfied that it has sufficient information at this stage. That is the Scottish Government's view on the items.

We might agree to write to the Scottish Government to indicate that we are content for consent to be given in relation to the UK statutory

instruments. However, I think that Keith Brown wants to make that conditional in some way or to tie it to our evidence session with the minister under agenda item 3.

Keith Brown (Clackmannanshire and Dunblane) (SNP): Yes. Let me also say that I think that it is less than satisfactory that we are being asked, without seeing final versions, to consent to regulations that will become the law of the land, even with the assurance that the Scottish Government has seen them. This committee and this Parliament are not the Scottish Government, and we have an obligation to satisfy ourselves about provisions that will be legal requirements. If we agree to take this approach, the difficulty will be that in consideration of items in the future—we are told that there are a lot more to come—we will not have the opportunity to do so.

In addition, it would be useful to have an assurance from the UK Government—I do not know who the appropriate minister is—that we are not going to be put in this position again and that we will get to see final versions of proposed laws before we are asked to consent to them.

Sandra White (Glasgow Kelvin) (SNP): I, too, have concerns, particularly about the blood safety regulations, and I concur with Keith Brown. The committee has not seen the final version. A draft might be with the Scottish Government, but we have not seen it and I am concerned that the committee will be agreeing to regulations that we have not seen. If that is the wish of the committee, and if the Scottish Government says that it is okay, I am happy to go along with the committee. However, I have concerns, given what happened in the past in relation to blood safety. We do not want to get caught by agreeing to something when we have not seen its wording.

The Convener: I absolutely appreciate the point. Unless members have other views—I know that we have discussed such matters previously—we should make a determination now about whether we accept the timing, subject to the minister's reply to a question in the forthcoming session.

In any case, we should also act on Keith Brown's suggestion that we write to the UK Government again and seek confirmation that, in the future, final versions of secondary legislation will be available as a matter of course, in line with our timetable. After all, that is the purpose of having an agreed timetable.

As long as the minister is able to assure us this morning that he will come back to us if there is any change in the policy substance of the regulations, do members agree to the Scottish Government giving consent, in line with the timetable?

Members *indicated agreement.*

Subordinate Legislation

National Health Service (General Dental Services) (Miscellaneous Amendments) (Scotland) Regulations 2018 (SSI 2018/300)

09:41

The Convener: Item 4 is consideration of an instrument that is subject to negative procedure. The regulations simply delay by a year the date of implementation of electronic payments for orthodontic treatment. Members have no questions and do not want to make any points on the regulations. Do members agree that we should make no recommendation on the instrument?

Members *indicated agreement.*

European Union (Withdrawal) Act 2018

General Food Law (EU Exit) Regulations 2018

General Foodstuffs Hygiene (EU Exit) Regulations 2018

Specific Foodstuffs (Hygiene) (EU Exit) Regulations 2018

Contaminants in Food (EU Exit) Regulations 2018

Quick-Frozen Food (EU Exit) Regulations 2018

09:42

The Convener: I apologise—I skipped agenda item 3, which is more EU-related legislation; we will take that item now. I am delighted to welcome Joe FitzPatrick, the Minister for Public Health, Sport and Wellbeing, Neel Mojee, who is a solicitor from the Scottish Government legal directorate, and Elspeth Macdonald, who is head of strategy and policy at Food Standards Scotland. They are here to address the committee's questions on a number of statutory instrument proposals from the UK Government.

I invite the minister to kick off with an opening statement.

Joe FitzPatrick (Minister for Public Health, Sport and Wellbeing): Thank you, convener. Good morning and thank you for providing this opportunity to clarify further why I am recommending that the committee consent to these UK-wide statutory instruments applying in Scotland.

As you know, the Cabinet Secretary for Government Business and Constitutional Relations wrote to the conveners of the Finance and Constitution Committee and the Delegated Powers and Law Reform Committee on 11 September, setting out the Scottish Government's views on EU withdrawal. He said in that letter that we must respond to the UK Government's preparation for a no-deal scenario as best we can, despite the inevitable widespread damage and disruption that such a scenario will cause. It is our unwelcome responsibility to ensure that devolved law continues to function on and after EU withdrawal.

The rationale for the proposed changes that these instruments will make is to ensure the continuation of important consumer protections provided by the current EU food and feed regulatory regime, to maintain the high standard of food and feed safety and hygiene that we currently benefit from as a member of the EU.

It is clear that the committee understands the importance of the legislation. Given the legislation's complexity, it is understandable that you asked for additional information and clarification, which I have provided to you in writing.

In essence, the additional information related, first, to why the committee had originally received only eight days for scrutiny. That was due to the timing of the notification of the proposals from Westminster, which coincided with the Scottish Parliament recess. I am pleased to advise—as I did in writing yesterday—that officials have worked with their counterparts to negotiate revised laying dates at Westminster, which now gives the committee its full 28 days from the original notification being made. That is obviously very welcome.

09:45

Secondly, the committee asked why the instruments had been categorised as category A as opposed to category B, as described in the protocol agreed between the Scottish Government and the Parliament. I provided more information in response to your questions. It is fair to say that categorisation is intended to be a guide to the committee, to assist with overall prioritisation, but the committee is of course entitled to ask for evidence. Hence we are happy to attend your meeting today.

Thirdly, you asked for clarification in relation to the possible implications for the proposed regulations of the recent BSE case in Aberdeenshire. I have written to confirm that the regulations are not directly related to BSE controls and that there are no impacts in relation to them. The instruments do not modify the principles or technical standards in EU law, which has served us so well; they are about ensuring the law's continued operability should there be no deal between the UK and the EU by the end of March next year, which is a situation that I am sure that we all want to avoid.

The EU laws that are covered by these fixing instruments are concerned with general principles of food law, technical food hygiene standards and limits and levels of contamination in food. The instruments provide the mechanism by which the retained EU law in these areas might be modified in the future, if and when that is considered to be required.

As you will fully expect, we have ensured that the regulations provide for any such modifications

in the future with regard to Scotland in respect of the devolution settlement. None of us wants to find us leaving the EU against our will and with no deal on 29 March 2019, but we must ensure that, should that happen as a consequence of the UK Government's actions, there is a sound legal basis to the regulatory system for food safety to ensure that we can continue to protect public health.

I hope that that is helpful, as I hope that my written responses were.

The Convener: That is indeed helpful, thank you, minister. Success in encouraging the UK Government to abide by the agreed timetables and acknowledge that Scottish Parliament proceedings operate to a different timetable from that of the UK Parliament is important, so your comments are welcome. Having got the right result in your discussions, are you content that a positive precedent has been established for the approach to further items of legislation of this type as they come forward?

Joe FitzPatrick: We have to recognise that we are to some extent subject to the timetabling of Westminster in relation to orders, so there might be a challenge, but it is very important that we continue to press the rights of this Parliament to scrutinise instruments and I hope that the message has got through to Westminster, to some extent.

Alex Cole-Hamilton (Edinburgh Western) (LD): Thank you for coming to the meeting today, minister. I want to ask about accountability. How confident are you that Food Standards Scotland has the requisite skills, competency and preparedness to take on the functions that are designated by the statutory instruments?

Joe FitzPatrick: The functions that will transfer to Food Standards Scotland are quite limited and are in line with the role of FSS as defined in the Food (Scotland) Act 2015, which set up FSS. Food Standards Scotland's accountability remains unchanged and is directly to this Parliament.

Alex Cole-Hamilton: On that basis, on accountability for the functions described in the instruments, are you confident that we will still have the whip hand in the future?

Joe FitzPatrick: Yes, absolutely. There is no change to the accountability of Food Standards Scotland. It is an unusual body, because other similar bodies are accountable directly to ministers. Food Standards Scotland is directly accountable to Parliament.

Keith Brown: I do not agree that getting the UK Government to change the deadlines was a success. It seems utterly pointless to change the deadlines if we do not actually get the detail of what is being proposed. The briefing note that we received says that the process asks us to take a decision on legislation without actually having seen the detail of it, which I think is a difficult position for this committee to find itself in.

I hope that the Scottish Government would support the idea that it is important not just that Westminster complies with the timescales and—apart from anything else—takes into account that we have a recess, just as Westminster does, but that it actually gives us the detail. We do not have the detail. We are having to rely on what the Scottish Government says it has seen from the UK Government, which I do not think is enough for the Parliament or the committee to go on.

More particularly, can I ask you about the potential for policy divergence, which is raised in our briefing note? If we have policy divergence—and I appreciate that this applies only in relation to a no-deal scenario—does that open up the possibility that the UK Government, acting on its own, could prescribe for different parts of the UK the acceptance of chlorinated chicken, for example, in the context of hygiene and foodstuffs regulations, thereby undermining the position that the Scottish Government or another devolved Administration was taking if it did not want to accept chlorinated chicken?

Joe FitzPatrick: First, the whole process is highly unsatisfactory, and we knew that that was going to be the case. That is why the protocol between the Scottish Government and the Scottish Parliament was formulated as it was; we expected to be in this position, in which we are having to consider regulations without seeing the final drafts. The protocol was established for exactly that reason: to make sure that there was the opportunity for scrutiny. Neel Mojee might talk about the timescales in that regard.

Clearly, if the instruments that are laid are not in line with what we have been told to expect and what we have told the committee, we will have to take a view. We might come back to you and say, "The orders are as we expected, and that is great. We recommend that you continue." We might say, "The orders are slightly different, but we still think we should continue, as before," or, if there is a significant change, we might say, "The orders that have been laid are not what we were expecting and therefore we do not recommend that they are approved." We would then have to look at other steps that we could take.

On future divergence, you may rest assured that I would not be recommending the instruments to the committee if they gave powers to the UK ministers to provide for future policy divergence against the wishes of this Parliament and the Scottish Government. We expect that the instruments that are laid will respect the devolution settlement. If in the future the UK Government

decides to go down the route of wanting to be able to have chlorinated chicken, perhaps so that it can have a deal with the United States, then under the orders as they are drafted we will be able to diverge from that and ensure that we maintain the higher standards that the EU maintains.

One of the big risks here—which is not directly related to the regulations that we are considering—is the loss of our access to the European Food Safety Authority, which I think is a gold standard internationally. That is not related to the instruments that we are talking about, but clearly it would be a matter of concern if, in the case of a no-deal Brexit, we lost that wealth of expertise.

Keith Brown: You are quite right. It is also very worrying that we will no longer be involved in the rapid alert system for food and feed. I will not ask a question about that, but the fact that we are withdrawing from some European norms was mentioned.

I want to go back to the point about the information that we have before us. I understand the point that has been made about what the protocol allows, but the reason for that is not to do with anything that the Government or the Parliament has done; it is there because proposals have been made so late in the day. That is why we are now in this position. Do you accept that it cannot be right for a legislature to agree potential new laws or legislation without first having sight of the details?

Joe FitzPatrick: The whole process is highly unsatisfactory. Neel Mojee might want to talk a little about the timings in respect of what he has seen of the draft instruments and giving me advice to pass on to the committee.

Neel Mojee (Scottish Government): Yes. In most cases—and certainly in the case of the instruments that are before the committee—the Scottish Government has not seen the final drafts at the point at which we have presented the notifications. The SIs are still being finalised ahead of being laid at Westminster. We try to provide as much detail as we can in the notifications, taking account of the fact that the SIs are not final and are not yet in the public domain. At the official, policy and legal levels, we see drafts from the FSA at every iteration.

Elspeth Macdonald (Food Standards Scotland): Members of my team are working very closely with their counterparts in the UK Government and the Food Standards Agency, and we have regular sight of how the draft instruments are developing. Obviously, we are working very closely with our legal advisers in the Scottish Government, so the information that we are able to provide to the committee is provided on the basis of our having been very closely involved in the process.

As Neel Mojee said, the texts are not completely final yet, but we can provide the assurance that we have been working closely with our counterparts. Our focus has been on ensuring that there is on-going and continued protection of public health and ensuring that we can protect the interests of the Parliament and of the Scottish ministers to make determinations in relation to Scotland.

The Convener: I think that the minister is confirming that, in relation to the items that we are discussing and other items, should there be changes in substance after this stage, he will revert to the committee and not proceed.

Joe FitzPatrick: Absolutely. I would revert to the committee and say why we were suggesting whatever.

The Convener: Okay. Thank you very much.

David Stewart (Highlands and Islands) (Lab): I thank the minister and the officials for coming to the meeting.

It is clear that there is a lot of vagueness in the Brexit negotiations. We know from today's discussion that, if we put through the General Food Law (EU Exit) Regulations 2018, we will revoke Commission regulation 16/2001, which set up the rapid alert system for food and feed. As the minister knows, the European Commission has made it clear that, thanks to that alert system, food safety problems across the whole of the EU and the European Free Trade Association countries have been averted. We know categorically that that will disappear. What recent discussions have you had with the UK Government to set up a UK-wide system to prevent problems from happening before they result in major food safety problems in the future?

Joe FitzPatrick: You are right. Those are significant matters that have to be resolved. It is clear that the best way of resolving them would be our being able to remain in the EU. If not, a Norway-style deal would allow us to have access to all those protections. There is still hope that we will not end up with a no-deal Brexit, but we have to plan for the worst-case scenario.

I understand that, if there is a deal, there would be legislation that would withdraw the instruments and put us back on to a better footing. Work is on-going between FSS and the Food Standards Agency to look at what frameworks we need to put in place for March next year in the event of a no-deal Brexit. Elspeth Macdonald can talk about that.

Elspeth Macdonald: We have been working very closely with our counterparts on no-deal contingency planning. Although consideration of

the instruments that are in front of the committee and lots of other instruments is part of that work, a huge amount of operational readiness contingency planning is also required.

We recognise that, in the event of no deal, we would need to address the loss of access to EU systems, so we have been working with our counterparts in the Food Standards Agency on how we could develop replacement systems or arrangements in which we would continue to get information about food safety risks in other parts of Europe and member states that are still in the EU. There are other ways in which we can try to ensure that we continue to have access to that information so that we can act quickly to protect the food chain, but we completely recognise that the loss of access to those systems would bring significant changes to how we have to operate. A lot of planning is going on behind the scenes to address those points.

David Stewart: Obviously, there is a lot of complexity, but simply replicating the Europe-wide model in the UK is not rocket science. How far down the track are we? Is it very likely that that will happen? Is there a plan B to have a draft UK rapid alert system for food and feed? Has something recently happened about that?

Elspeth Macdonald: There are different layers of access to the rapid alert system for food and feed. Obviously, a member state will have the most detailed level of access, but the UK would still be able to have a public level of access outwith the EU. However, there are other systems. For example, there is the international network of food safety authorities, which is a more international system that draws information from the RASFF. That would allow us to have timely and up-to-date information about food safety risks.

10:00

We already have very close working relationships across the four countries in the UK, and we are already pretty efficient at working collaboratively across the four countries in dealing with food incidents and ensuring that we exchange information. That approach operates pretty well at official level, and I do not see that being affected. It is more about access to the EU and the international information.

David Stewart: I do not disagree with the points that you have made, but it is clear that we have in the rapid alert system a gold standard across the 28 countries in the EU plus the other four countries. You are suggesting a system that is lower than that. Could you replicate what currently happens with the other nations in the UK very quickly if we withdraw from the EU with no deal?

Elspeth Macdonald: That is certainly the intention but, obviously, until the final details of the contingency planning are determined, I cannot provide the assurance that that would be every bit as good.

David Stewart: But we are withdrawing from the EU, and the instrument will withdraw us from the scheme.

Elspeth Macdonald: In a no-deal situation, the UK would not be able to remain within the rapid alert system for food and feed. Were there to be a negotiated settlement and a deal between the EU and the UK, the situation might be different.

The Convener: The Scottish Government has responsibility for the categorisation of the instruments. That falls to you. The General Foodstuffs Hygiene (EU Exit) Regulations 2018 and other regulations appear to confer powers on ministers. I think that the question why they have been categorised as category A, which covers proposals of a technical nature, rather than category B, which covers proposals of greater substance, was raised with you. Will you respond to that?

Joe FitzPatrick: If members look at the protocol that was agreed with the Parliament, they will see that, in effect, category A covers technical proposals and proposals in which there is no policy change. Although powers are moving, the instruments would not change anything on the ground, so one minute before Brexit and one minute after it the technical application of the regulations would be the same. There are no policy choices in them. However, the Government makes judgment calls, and it is clear that that is simply guidance. It is about helping to prioritise. If the committee decides that it wants to be more robust in its scrutiny, I absolutely respect its right to do that. It was written into the protocol that the committee can take a different view. The approach does not affect the committee's view; it is aimed at helping it to prioritise.

The Convener: I understand.

Brian Whittle (South Scotland) (Con): Good morning. I want to follow up on the point that David Stewart made. He mentioned that the EFSA is the gold standard. Given that the UK has helped to develop that gold standard—in fact, it has probably been one of the key driving forces in developing it—why do you consider that, with no deal, we would have a lower standard? The UK drove those standards in the first place.

Joe FitzPatrick: We have to recognise that, in the event of a no-deal scenario, we might not have access to the EFSA in the way that we do now. To be clear, it is not just EU nations that have access to that agency, so it is possible that, if there is anything better than a no-deal Brexit, we might

manage to have access to it. It is the gold standard. It is clear that it is our job to ensure that the law works as it should, which is what the instruments would do, but, if we do not have access to the EFSA, we will need to ensure that we have something else in place to maintain standards at the same level.

The Scottish Government's view is that we would want to maintain standards that are as closely aligned as possible to those that our European neighbours have, so there are on-going discussions between FSS and the FSA in order to try to ensure that we have that backstop. If we cannot be part of the EFSA, we need to do something else. That is why discussions are on-going.

All of that work is going on for the worst-case scenario. I think that everyone in the room hopes that we will not get to that. A huge amount of effort is being spent on dealing with a scenario that should have been ruled out by now. That is the most frustrating thing. A huge amount of the Parliament's, the Scottish Government's and Food Standards Scotland's time is being used to prepare for a worst-case scenario that we all hope will not happen.

Brian Whittle: I asked a very specific question. The UK has been a driving force in developing a gold standard in the European Union. Why do you think that we would reduce our standards with no deal?

Joe FitzPatrick: I do not think that. We will have to work to ensure that we can set something up to maintain standards, whatever they are. Work between the FSA and FSS is on-going to ensure that we can maintain those standards. That has to be our aim. The idea of chlorinated chicken horrifies me.

The Convener: I think that that point is understood.

Miles Briggs (Lothian) (Con): Good morning. Following David Stewart's and Brian Whittle's questions, it is important to get on the record that, post-Brexit, food standards legislation will be just as strong as it currently is. Scaremongering does not help that debate.

On a specific point, I take it that you accept that it is best to deal with the regulations on a UK-wide basis.

Joe FitzPatrick: I am recommending that the specific instruments are accepted on a UK-wide basis. It is important that the regulations respect the Scottish Parliament's place and the fact that the matters are devolved. Therefore, in any future arrangement between the FSA and FSS, it is important that Scottish interests are protected. I am sure that you think that the Scottish Government will ensure that that is the case.

I agree that it is important that we look at matters through clear glasses rather than through rose-tinted or more opaque glasses. The instruments are about ensuring that the law the day before Brexit withdrawal is maintained the day after.

The Convener: Thank you very much, minister. I think that that deals with committee members' questions. I am grateful to you for your time. We will no doubt be in touch again on many of the instruments in the very near future.

I suspend the meeting briefly while the panel changes.

10:08

Meeting suspended.

10:11

On resuming—

Human Tissue (Authorisation) (Scotland) Bill: Stage 1

The Convener: The next item is the first of our public evidence sessions on the Human Tissue (Authorisation) (Scotland) Bill. As everyone in the room I think will know, the bill proposes to introduce a system of deemed authorisation for organ donation in Scotland. We have two sessions today to hear from patient and public representative groups.

I welcome to the committee David McColgan, the senior policy and public affairs manager for devolved nations with the British Heart Foundation; Harpreet Brrang, the information and research hub manager with the Children's Liver Disease Foundation; and Gillian Hollis, who is attending in a personal capacity as a lung transplant recipient. I welcome you all to the committee and thank you very much for offering to give evidence today, and indeed for your written evidence, which I know colleagues have found very informative.

I start by asking members of the panel what the need for legislative change in this area is. Do you think that deemed authorisation under the bill will result in a marked difference in practice?

David McColgan (British Heart Foundation Scotland): Thanks for inviting us to the committee. It is great to see this bill coming back to the Scottish Parliament.

The British Heart Foundation has been pretty clear in our support for opt-out over the past several years. Our biggest concern is the gap between the number of organs that are needed and the number of organs that become available. The biggest challenge for anybody looking at organ donation is the gap between the number of people who are willing to donate after death and the number of people who get around to donating. A number of polls have shown that, in the UK, about 80 per cent of the population would be willing to donate their organs, but only 51 per cent of people in Scotland get around to registering their wishes. That gap is a challenge.

One of the other big challenges is the number of people who register their willingness to donate but do not follow through to donation. The committee will be aware that family consent rates in Scotland are the lowest in the UK, and that has been the case since 2014. One of the challenges is how we increase family consent. I think that the experience in Wales is crucial. In Wales since 2015, when opt-out was put into operation, there has been a 50 per cent increase in family consent rates, up to about 72 per cent currently. There have been a lot of myths about follow-through to donation in Wales, but what we are really interested in is the family consent rate. I think that soft opt-out is a very good way of increasing family consent rates, and the evidence is there to show that.

10:15

Harpreet Brrang (Children's Liver Disease Foundation): I completely agree with all those points. I also think that the bill is trying to encourage people to make a choice. It is not saying, as some members of the public might think, that they are being forced into donating the organs of a family member. It is encouraging people to make a choice about it. That is another opportunity with the bill.

Many of the families we work with, who are the families of children with a liver condition, say that, until their child was going through the treatment and needed a transplant, it had not come into their minds to consider organ donation and then, as soon as their child needed a transplant, they registered as soon as possible. Often it is the fact that people do not think about it beforehand that leads to them not taking action to sign up. This pushes them to make a decision either way.

The Convener: Thank you.

I know that Gillian Hollis is here in a personal capacity rather than as a member of the Scottish donation and transplant group. Feel free to answer and we are certainly interested in hearing your views.

Gillian Hollis: Like everyone else around this table, I am very pro any means to increase the number of organ transplants that take place each year. I have seen the benefits myself. There have been 15 fantastic years. Over those 15 years, the Scottish Government, NHS Blood and Transplant and the national health service have done a lot of things to increase the number of transplants that take place. First, I think that we should be celebrating that and the achievements of the past 15 years, because there have been real inroads made.

Immediately after my transplant, I was completely in favour of opt-out; I thought that it was a no brainer. Why would you not? I have been working on committees and groups associated with transplantation for the past six years in particular and I have found that my view has changed a bit. I am not convinced that moving to an opt-out system is the right means of increasing the number of organ transplants. I think that the situation is far more nuanced, and I can see from the briefing note, the submissions that have come in and the comments that people have made that

we will be talking about some of those nuances in this session.

The Convener: Indeed.

An aspect of both the current law—the Human Tissue (Scotland) Act 2006—and the bill is that neither formally provides for family objection, but I think that it is fair to say that they are both designed in the expectation that, if a family is not content, a transplant will not proceed. Do witnesses feel that not explicitly referring to that in the bill is appropriate, or should there be an explicit reference to it in the bill?

Harpreet Brrang: There might be a lot of backlash from not making it clear to people what the family's role is. I noticed in the briefing notes that there was a discussion of the fact that families can provide information in relation to deemed authorisation to say whether their family member would have changed their mind or not agreed with the decision to take their organs, but it might not be overly clear what information they need to provide and how to provide it. As long as that is made clear enough, and it is clear that they still have a say and are still involved in that process, I think that the opt-out approach could still work. I think that it is about changing people's perceptions of what it is.

Gillian Hollis: I think that it is a hard thing. Certainly, the idea of the 2006 act was to try to take away the right of veto of relatives, but my experience of speaking to medical professionals on this issue is that, when a relative is saying, "I do not want this to go ahead," it is the front page of the newspaper scenario, and no doctor is going to go ahead against the vehement reluctance or prohibition of the relative.

My experience on this was coloured somewhat by taking part in a BBC Radio 4 discussion on opt-out a few years back. I went in very naive, I suppose, and very positive, and I was quite taken aback. There were a lot of very strong views on this in the phone-in, and relatives felt very strongly that they should play a part as well.

Alex Cole-Hamilton: It is remarkable to hear your story. My interest in this area comes from personal experience as well. My close childhood friend needed a transplant during the 30 years of his short life. He got that but, sadly, he died very shortly after because of complications. He drove my interest in this in favour of an opt-out. I am interested to hear you unpack the journey as to why you were very in favour of that and now are less so.

Gillian Hollis: When I was reading the transcripts of the House of Commons meetings at which the English bill—the Organ Donation (Deemed Consent) Bill—was discussed last week, I was very struck by the fact that it is a really feel-good bill and a good thing to do; it feels like the right thing to do to move to an opt-out system. It was only when I looked at some of the implications, talked to some of the specialist nurses about the discussions that they have and heard the views of members of the public who got quite upset about the idea of the state having some control over their body that I realised that the issue is so nuanced and not as straightforward as I had thought.

My background is that I did a law degree and, ironically—this is before I was ill—medical jurisprudence and ethics was one of my subjects, so this is the kind of thing that I studied as a student and then have come back to and am actually seeing. I am intellectually interested in it, but I have found that I am less enthusiastic about the move to opt-out than I was 10 years ago. It is not because I do not believe in increasing organ donation. I just feel that there is the potential for a bit of a backlash.

David Stewart: What assessment have you made of the element of gift in the current system? I will start with Gillian Hollis, because her submission was very interesting on that point.

Gillian Hollis: I think that the fact that an organ donation is a gift is very important. I owe my life to my donor and their family, and the fact that they took an active decision to give a lung to me and a heart to the girl who had a transplant the same night as me in the same hospital and who I have kept in close contact with. We really appreciate that gift and it is a very important part of the process for both sides. Should the bill go through, it is very important that that element of gift is retained as much as possible, because it is people helping other people. A donation is a true gift.

David McColgan: The point about organ donation being a gift, which Gillian Hollis raised in her submission, is very important. The British Heart Foundation does not see moving to a soft opt-out system as removing that choice to make a gift. All we see it as is a change in the initial conversation. People will still be perfectly within their rights to opt out. People will be able to register their objections much more strongly and legally than they currently can.

Also, there is a reason why the British Heart Foundation does not support a hard opt-out that does not involve the family, as opposed to the soft opt-out. A big part of that is maintaining the positive choice to donate rather than a state-sanctioned donation, which a soft opt-out absolutely is not. We do not see the concept of gift being removed through a soft opt-out. We just see it changing the initial conversation.

Harpreet Brrang: In a conversation that I recently had with one of our Scottish families, the

idea of a gift was something that the mother explicitly said was a reason why she was completely in support of a soft opt-out approach. She said that, when her daughter received a split liver transplant, they were ecstatic, because if they had not received it at that time, their daughter would not be alive right now, but then she remembered that, for her daughter to get that liver transplant, someone else had passed away. They saw it as a gift, because someone chose to donate that liver. She said that she would feel slightly more uncomfortable about it if she thought that it had not been an active choice. With the soft opt-out approach, people are still given a choice. As Gillian Hollis said, the idea of a gift needs to be retained, for both sides.

David Stewart: How important is simplicity of message in the bill? In Gillian Hollis's submission, she said that it is

"quite a complicated language. Tell us if you want to donate. Tell us if you do not want to donate, and if you do not tell us anything we will presume you have got an authorised donation".

That seems complicated to me as a layman.

Gillian Hollis: That is what I feel from talking to people. There is work going on about the opt-out bill and people say, "Oh, I thought that that had gone through already." People are not aware generally of what is happening. I think that it is a complicated message and some of the terminology does not help. The term "deemed authorisation" is quite obscure. As I said in the submission, there are lots of double negatives possible with the terms "opt-in" and "opt-out".

I think that it will be challenging, but it is very important that the message is clear, because all of us want to do a good thing. We need to make sure that we convey that message as positively as possible but as simply as possible, so that we get it across. Especially when we are moving to a default position that the organs would go to donation anyway, it has to be simple.

David McColgan: It is interesting that when we had the debate about opt-in and opt-out when Anne McTaggart introduced her member's bill, we kind of defaulted to the position in Wales, where there was quite a movement during consideration of the Welsh Government legislation to retain the opt-in. The original Welsh Government legislation was going to get rid of the opportunity to opt in, but many people still want to make that positive choice while they are alive and many people are quite proud of carrying an organ donor card. That was one of the reasons why we retained opt-in.

I do not dispute Gillian Hollis's point about confusion about that, but we have to look at organ donation campaigns that have happened up until now. None of them has spoken about opt-out. We should learn from the experience in Wales, where there was an 18-month campaign and the vast majority—over 80 per cent of the population—understood the legislation. There is not much legislation that comes out of the Scottish Parliament that has that level of understanding. One of the reasons why the BHF really likes this bill compared to the English bill is that it puts a duty on ministers to communicate the legislation. That will be very important in the run-up to its implementation. Although the legislation may be confusing right now—and that can be said for any piece of legislation—what is important is the communication from the Scottish Government if the bill is successfully passed.

Gillian Hollis: I have a quick supplementary point just to say that we are unusual in Scotland in having the money that has been devoted to organ donation campaigns over the past few years. I think that all of us really appreciate that, as it has made a huge difference in getting the number of people on the organ donor register higher in Scotland than it is anywhere else in the UK. What is happening is against that background of getting money for campaigns and having good campaigns. I really appreciate that.

Harpreet Brrang: This is an opportunity to shift people's attitudes as well as the perceptions and the culture surrounding organ donations. The simpler you can make it—and it needs to be very, very simple—and the more effort and investment you put into raising awareness, the more effective this bill will be in increasing the number of organ donations.

David Stewart: My final question is a very general one. What is your assessment of the issue of deemed authorisation? Will it increase donation rates and save lives?

10:30

David McColgan: To expand on what I said in my introduction, nine of the top 10 countries in the world on donation rates use an opt-out system. The only one that does not is the United States. When we considered the Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill a few years ago, many people wanted to see what happened in Wales, because it has a similar healthcare system and a similar culture. The evidence there has shown that there has been a significant increase in family consent rates. Gillian Hollis touched on the issue of specialist nurses. The Young et al analysis of the Welsh experience said that specialist nurses found conversations to be much easier and families to be much more informed.

There has been an element of smoke and mirrors with what has happened in Wales. Organ

donations have not increased massively—it is estimated that they have increased by 20 per cent—but Madden's analysis of the legislation put that down to people's eligibility as donors. We cannot predict people's eligibility as donors, but we can try to shift the family consent rate. Countries that have high donation rates have high family consent rates. Scotland has the highest percentage of the population who are opted in to organ donation, but we are the lowest when it comes to the family consent rate. I think that that is where culture change is necessary. From the international experience and the Welsh example, we believe that we can shift family consent rates by using an opt-out system.

Emma Harper (South Scotland) (SNP): I should begin by reminding folk that I was a member of a liver transplant team when I worked in Los Angeles. I am interested in increasing donation rates. As you mentioned, that will involve a culture change. No single measure will increase the number of donors. You have already said that the Government has a duty to communicate with people. How do you expect that communication to be delivered?

David McColgan: As I said earlier, the lead-up to the implementation of the legislation in Wales involved a highly effective 18-month communication campaign. It is also interesting that, since the introduction of the opt-out legislation in Wales, there has been an increase in the number of people who have decided to opt in—more people have got round to doing it.

I think that communication is key. The Welsh Government used a multichannel approach: it did TV and bus stop adverts, it had a great radio campaign and there was a whole raft of literature that was used by the NHS and organisations such as the BHF in Wales. We must understand that we live in a multicultural, multilingual Scotland, so we need to make sure that any legislation or campaign is targeted at all the communities in Scotland. I think that the Scottish Government's recent seven words to save seven lives campaign was really good. It is clear that the Scottish Government has something that is working for it when it comes to getting people to opt in. What we now need to look at is how we achieve a shift on family consent. I think that any sustained campaign will be effective, given the Scottish Government's experience, historically.

Harpreet Brrang: Deemed authorisation on its own does not necessarily mean that organ donation rates will increase. It is necessary to take a holistic approach, as part of which communications with the public should start as soon as possible. For example, as I mentioned, many of our families do not join the organ donation register until they are affected by the issue or understand what the register is there for. We could promote organ donation by showing people the effect that it has and how it can save lives, because many people—especially in certain cultures—do not like to talk about death or to think about that stage of their life. We should start the communication process as early as possible. Certain groups—older generations, for example—do not like to talk about that stage because of the fear of it. We need to enable people to talk about the issue more openly. That is partly about the language that we use and the routes that we provide. We should offer different routes of communication rather than always communicating through online portals.

Gillian Hollis: There needs to be a continuation of what is going on at the moment, whereby there is increasing acceptance of talking about organ donation publicly. The whole-hospital approach involves all the staff, regardless of which department they are in, being encouraged to think about organ donation rather than it just being an issue for intensive care or accident and emergency departments. There has been a shift towards having discussions about organ donation as a usual part of end-of-life care, which has been important. Such smaller cultural changes will make a difference. The more regular on-going education campaign that starts at school age is very positive and helpful.

Miles Briggs: I would like to follow up on Emma Harper's question. I notice from the submissions that countries that have a soft opt-out, such as Israel, Belgium, Norway, Spain and Sweden, have higher donation rates. That is particularly true of Spain, which introduced its system in 1979. Is there anything that Spain has done differently, or has there simply been a cultural shift over time?

Gillian Hollis: I suspect that the committee will have a bit more information on Spain, as it is held up as the model for organ donation and how to get organ donation rates up. If we look more closely at the figures, we find that it was not until 10 years after the opt-out was brought in that there was a big increase, and that was the result of infrastructure changes to do with how the teams were organised and the availability of retrieval teams and operating theatres. A lot of developments took place. In our submissions, all of us have talked about the need for a raft of proposals and new infrastructure to come in at the same time in order to make a difference in the organ donation rates.

David McColgan: There is a range of opt-out systems in the international evidence. Every country that runs an opt-out system has brought in legislation. Opt-out legislation is the first of the three pillars that the BHF looks at. Pillar 2 is continued infrastructure investment. Countries that

run an opt-out system have high availability of intensive care unit beds, which is very important. Pillar 3 is staff training, which involves continued investment. Spain is a very good example. It brought in legislation in 1979 but did not create a national co-ordinating body until 1989. It ran a big media campaign in the early 1990s, which is when the climb became evident. I think that it was Harpreet Brrang who said that legislation will not be the magic bullet and that a whole package of measures need to be taken. We need to continue to invest and to train staff, as well as starting on the process of cultural change in Scotland.

Keith Brown: I thank the panellists for their submissions and for coming along today. In particular, I thank Gillian Hollis—the clarity and brevity of her submission was great. I very much agree with her point that the message that we are trying to send is complicated. I also agree with what she said about how well things have been done over the past 15 years and the dedicated resource that she mentioned.

My particular interest is in the rights of the individual. If an adult takes a decision that they want to donate, do other family members have the right to override that? A related issue with presumed consent or deemed authorisation is whether the state has the right to say that it will take control of a person's body unless they have expressed a wish otherwise. If we continue to allow family overrides, is there a danger that that is more likely to happen in a situation in which a family is trying to override deemed consent than it is in a situation in which explicit consent has been given?

The Convener: Who would like to start? Mr Brown has asked a number of important questions.

Gillian Hollis: I think that that gets to the nub of an extremely difficult issue, on which we will not get consensus. In theory, the 2006 legislation allowed doctors to override the relatives' consent, but many people still said, "We do not want that." There are very strong views on both sides. On one side, people think, "If I make a decision, I want that decision to be carried out; I don't want my relative to be able to do that." On the other side, there is the relative at the bedside on the day who says, "You're not going to take the organs away from my loved one". It is a very personal issue. I would probably sit on the fence a bit; I am not sure what the correct answer is.

Harpreet Brrang: It is a difficult situation, as Gillian Hollis said. If family members have a very strong opinion, they might see deemed authorisation as the state taking control, but that comes back to the need for education. It is a difficult issue. How it is perceived is a matter of opinion; it also depends on how the medical professionals deal with it at the time. The training that staff have should encourage them to take a cohesive, collaborative approach with the family members. That might ease the tension a little, but I think that it will always be there.

David McColgan: To reiterate what Gillian Hollis said, our experience of working with clinicians on the issue is that no clinician will ever go against a family's wishes. Gillian Hollis mentioned the front page of the newspaper scenario—we might have spoken to the same person. Doctors will never override a family who says no on the ground that, "The law says we can do it." When it comes to deemed authorisation, state ownership and the right of the individual, the family's role in the process is made significantly easier when the wishes of the individual are known. We know that families are less likely to object to donation if they know that their loved one wanted to donate. It would be the same with the flipside. If the family knew that their loved one had opted out, their role would become much easier—it would just be a case of confirming their wishes.

Through the consultation on Anne McTaggart's bill, we met families in which the children were all for organ donation, but the parents said that they would not do it. That is a challenging conversation to have as a family, but we want to make such conversations easier and more likely by having an opt-out system. That will help to take out the challenge of the legalese around state ownership, because the family will understand its role in the process. In the current system, I am not sure that it is understood how often the family is involved.

Keith Brown: From my reading of the bill, what is proposed does not make the family's role any clearer. There is nothing explicit in the bill on the role of the family. I am interested in what you think allows the rights or views of the family to supersede the expressed wish of the potential donor either not to donate or to donate. I understand your point about medical professionals—perhaps it would be easier if the law set out the position—but what is your understanding of what gives the family that right? Obviously, there is the family nature, but what if that person has made a decision?

The other point that I tried to make is that, if the bill goes ahead as planned and families continue to have that non-legally acknowledged right, are they not more likely to challenge it when there is deemed consent than when someone has explicitly consented? The family might think, "They never agreed to this; it's just because it is the law, and we are going to object for that reason." Where do the family's rights derive from? Will the bill be counterproductive as a result of the family veto?

10:45

David McColgan: On the point about deemed consent, the bill is clear that, if someone has not opted in or opted out—if they have not made the explicit statement, "I do not want to donate"—they are in to donate. The person might have said to family members, "I don't want to donate, but I have never got around to opting out," and those cases are written in. I completely agree that there is a challenge around deciding when the family has the right to overrule. If someone has opted out, we would argue that the person is out and the family should not override their decision, and the same applies if someone has opted in. However, we know that that already happens, for a number of reasons. I would never want to find myself in a position where I have to make the decision to donate someone's organs if they had opted out or even if they had opted in, because it is a high-stress situation.

There will always be cases in which family members feel that they want to go against the wishes of their loved one. The Parliament may decide whether to make it possible to do that, but BHF does not have a view on that. You will probably find that there are views on both sides of the aisle on that issue as you go through the evidence sessions and among the public.

Brian Whittle: I want to pick up on David McColgan's point that a healthcare professional will never go against the will of the family. That is a dangerous statement, and I do not agree with it. We should not be putting those kind of decisions on to healthcare professionals. On Keith Brown's point, do you not agree that the bill, if it goes forward, must have absolute clarity so that there is no wriggle room and we do not put those kinds of decisions on healthcare professionals? I am not convinced of your argument on that.

David McColgan: The point on healthcare professionals is purely anecdotal. I have not polled all healthcare professionals, but that is a common message that is given to us. It is a message that we wrangle with when we are thinking about legislation on the topic. On the point about clarity, the clearer the bill is, the better for me and for everyone, and the panel has said that. The less complicated it is the better, and the easier it is to communicate the better. That is important.

I do not have the figures to hand, but we have only five, six, seven or eight cases where families have objected to their loved one donating even though they had opted in. It is interesting to go back and understand what those conversations were like and why, under the current legislation, the clinicians did not say, "We have the right to do this because your loved one has opted in." It is interesting to look at why that happens now and in what percentage of donations clinicians say, "We're going to do it." I think that it is a very small percentage, although I do not have any evidence to back that. Our Welsh colleagues have been running this system for two years. I am not sure whether the committee will hear from anyone from Wales, but there will be a wealth of experience there already about how those conversations have gone and what the system is like.

Gillian Hollis: That is where the bill proposes a very big change in the default position. The deemed authorisation when someone has not recorded an opt-in or an opt-out has to be made clear to people before you can enforce it. It must be clear that that is what will happen and that relatives should not be able to override that. That is a very big change and will need to be communicated. If it is communicated properly, it will be all right not to accept relative overrides.

Harpreet Brrang: The bill says that relatives would need to provide evidence or information. If the bill is very clear about what that is, that will make it not easier, but a little clearer for the professionals who are involved in the process. At the moment, that might not be clear and it would just be interpretation.

Alex Cole-Hamilton: I, too, would like to ask about the family override. In our informal evidence session with specialist nurses, they talked us through the process by which that conversation happens currently. They revealed to us that literally hundreds of questions are asked of families at the most difficult time when they are coming to terms with the sometimes very sudden loss of a loved one. We were told that that is a demonstrable deterrent to families allowing consent. Families will often bail on that process, because it becomes too long and drawn out and they need to collect themselves. Can we do something in the bill to reduce that bureaucratic pressure or are we, by necessity, going to create further bureaucracy in the process?

Gillian Hollis: You are absolutely right. My understanding from the specialist nurses and from reading papers on why donations did not go ahead is that the length of time in the process, the number of questions that had to be answered and the bureaucracy that had to be gone through were very big factors behind that. Fifteen years ago, my husband's cousin's husband died in a motorcycle accident. She went through the donation process for her husband and was horrified by the number of questions that she had to answer. She said, "Frankly, I got halfway down the first page and then said, 'I can't do any more of this.'" That was because, as Alex Cole-Hamilton pointed out, the circumstances were so difficult. I am not sure of the extent to which the bureaucracy is giving a better understanding of what can and cannot be transplanted. We can do more and we can

transplant more organs now and I am not sure whether the extra bureaucracy is essential, but I would certainly welcome anything that reduced it.

From a patient recipient point of view, the forms that we are being asked to sign are now a lot more bureaucratic and longer than ever. I just signed a one-page form saying, "I will accept any organ and the risks that come with it." People who go on the transplant list are now asked to sign pages of forms that go through the different types of donors and different risks that might associate with each of them. It is a very difficult position. I do not know how much of that bureaucracy is necessary but, if it can be reduced, I would welcome that.

David McColgan: BHF does not have an opinion on the issue, but I think that we would agree with anything that makes the process easier and more streamlined for families, as long as it is still clinically and medically safe. We defer to our specialist nurse colleagues who operate that.

Alex Cole-Hamilton: We were told by the specialist nurses that the questions very much mirror those that people answer when donating blood. I understand that there is a need for clinical surety about what is coming in. However, that is not done in isolation. With blood, as with organs, tests are done to check that it is clean and that there are no contaminants or diseases. We are asking very vulnerable families very intimate questions to which they may not be able to give an accurate answer. If the questions are about sexually transmitted disease or lifestyle factors, the family may not want to reveal something that was going on in their family member's life or they may not know. I do not think that much surety can be derived at that time, so I wonder whether we can dispense with part of that to give families comfort and respite from fairly arduous questioning. Is it still clinically necessary to probe those areas?

Gillian Hollis: Wearing another hat, I sit on the Advisory Committee on the Safety of Blood, Tissues and Organs, which advises the UK and devolved Governments on matters to do with the safety of blood, tissues and organs for transplant. We are doing quite a lot of work in that group to increase organ donation by looking at organs from people who might previously have been considered too high risk or whose particular organs might have a risk attached to them. We have been doing a lot of work on categorising different risks and how the organs might be utilised safely. That has been very successful in increasing the number of organs that are becoming available and that can be used for transplant and increasing the number of transplants. There is a balance between getting the safety part right and not doing things that make it far more difficult for the relatives to say yes to organ donation in the first place.

Harpreet Brrang: It would be fantastic if the bill could be used as an opportunity to cut down on the bureaucracy and the number of questions that people are asked at such a difficult and sensitive time. We cannot comment on how clinically safe it is, because we at the Children's Liver Disease Foundation are not medical professionals, but the bill might be the ideal time to consider that opportunity.

Sandra White: Gillian Hollis has answered some of my questions, and she is obviously involved in the matter. Have any organisations or groups been asked or consulted about the questions that are asked? Should the bill process be in part a consultation on that issue? Alex Cole-Hamilton is absolutely right that some of the questions that are asked are so intimate and people do not know anything about them. As part of the bill process, should we look at reducing the questions? Should that go out to consultation or should organisations such as yours be asked? I think that around 300 questions are asked.

Harpreet Brrang: Absolutely. We are all about advocating the patient's voice and speaking on behalf of the public and getting their opinions and views on things because, at the end of the day, it affects them. If you speak to family members who might have been asked those questions, you can derive from them what the most sensitive questions are and then work alongside medical professionals who know which ones are absolutely necessary. You have to involve a lot of stakeholders in that to come to the right approach.

David McColgan: My question back to Sandra White is whether we need legislation for those questions to be written or whether a recommendation can be made to NHSBT to look at the matter. We have to remember that the organ donation framework is not just in Scotland, England, Wales or Northern Ireland; it is a UK-wide framework. We need to work with colleagues across the UK on what questions would be appropriate across the UK and to understand the current set-up. I do not know when the issue was last reviewed, but I think that it is worth looking at. The committee has identified the issue, and it was identified a number of years ago when a former MSP spoke about his personal experience. Harpreet Brrang is absolutely right that there should be patient involvement and involvement of families that have been through the process. It would certainly be worth while taking that kind of approach to get the best answer.

Gillian Hollis: That recommendation would go to NHSBT, which deals with the questions on a UK-wide basis. As David McColgan said, it operates not just in Scotland. I agree with David

that it probably should not be in the bill, but a strong recommendation could be made to review the questions. However, I believe that the matter is being reviewed by NHSBT, because it is seen as a hurdle to increasing donor numbers.

11:00

David Torrance (Kirkcaldy) (SNP): Good morning. In Wales, deemed consent applies to people aged 18 and over, whereas in Scotland, deemed authorisation will apply to people aged 16 and over. Do you agree with 16 as the age at which deemed authorisation should apply?

David McColgan: We are happy with 16, because when we looked at this issue during the consideration of the previous bill, we saw that the legal age of consent in Scotland differed from that in the rest of the UK. However, if the consensus is that it should be moved to 18, BHF will not have any major opposition to that. The age of 16 was set in order to tie in with the age of legal consent.

David Torrance: I asked the question, because it can sometimes be very hard to engage with the 16-and-under age group. How can we give young people sufficient opportunity to express their wishes in advance of their reaching the age of 16?

Gillian Hollis: I think that it can be part of education in schools. I have done quite a lot of talks in schools, sometimes as part of the personal and social responsibility curriculum, and I know that the issue is being covered by at least some—and, I hope, a lot of—pupils. When I speak to pupils, the first thing that I stress is that I am not there to convince them all to sign up to the organ donor register. However, I do ask them to go home, discuss the issue with their families and find out their views. The discussion on organ donation can start early, and it probably has a place in the school curriculum.

Harpreet Brrang: I completely agree. The discussion can start in schools—and the earlier, the better. As Gillian Hollis has said, a lot of schoolchildren will go home and discuss the issue with their families. As a result, you can target family members as well as the children. If you educate people at a very early stage, the culture change can happen from that age range.

Keith Brown: I want to go back to David McColgan's point about the UK operating as one on this. If the bill were to be passed with 16 as the age limit for deemed authorisation in Scotland—the point that David Torrance made—would that introduce legal complications with regard to where organs could go in the UK?

The Convener: That is a good question to which there appears to be no immediate answer.

Gillian Hollis: It is a very good question—and it has me completely stumped. Although I live in Scotland, I had my transplant in England because the Freeman hospital in Newcastle is the nearest lung transplant centre, but I think that my lung came from another part of the UK that was neither England nor Scotland. I do not know the ins and outs of how the system would work.

David McColgan: We already have two systems in the UK: a soft opt-out in Wales and an opt-in in the rest of the UK. As a frequent traveller to Cardiff, I like to keep a note of this. Under the Welsh legislation, there is a residency period before the provisions apply—I believe that, in the Scottish legislation, the period is a year—and it means that if something were to happen to me in Wales, I would be treated under the opt-in system, not the opt-out system. I imagine that there is precedent with regard to, say, an English family visiting Scotland. If the person in question was under 18, the age would not default to 16; it would stay at the 18 age limit that operates across the rest of the UK, unless it was decided that that should be lowered, too. I think that there is precedent in the way that Wales operates its system, and we should look at that.

Keith Brown: My question was more about a 16-year-old in Scotland being a donor. Would there be a restriction on where their organs could go in the UK, given the presumption elsewhere that the donor must be 18 and over?

The Convener: I have a feeling that that is a question that we will have to put to the Government in due course.

Sandra White: I want to touch on pre-death procedures. When we spoke to individuals—we also had a private evidence session on the matter—we found that the issue was causing great concern in relation to situations in which a person might be deemed to be brain dead or their heart might have failed. Basically, they were asking whether the procedures would cause pain to a patient whose heart might have stopped, but whose brain had not. What is your view on a decision to carry out PDPs on patients who are not deemed to be dead? Obviously the issue will be—or might be—set out in regulations, but do you have concerns in that regard? Families and other people certainly have.

Gillian Hollis: This is another area that I have a better—though not perfect—understanding of. At one organ donation conference I attended, a doctor's whole talk was on the question, "When is somebody actually dead?", and he talked about the difficulties with the different definitions of death. It was an eye opener for me, because I had just thought that people were at one stage or the other. As far as pre-death procedures are concerned, it can be quite hard for a layperson to

understand that there are some criteria under which someone might be deemed to be dead, but there are things that can be done to make organ donation better in the circumstances.

I note from the Scottish Parliament information centre briefing that some people felt "distaste" for the phrase "pre-death procedures". It is definitely an issue, because the term sounds awkward and, indeed, quite nasty. However, it is not just a matter of giving something a different name. You have to be clear with relatives to ensure that they understand what is going to happen—and why it is going to happen—and that might involve having a discussion about the definition of death itself.

Sandra White: As a layperson myself, I did not realise that this was an issue. If something happens, certain organs will not survive if they are not transplanted. Quite apart from the fact that you would not want to ask anyone about anything that is called a "pre-death procedure", the issue that worried a lot of people was deemed consent or authorisation. They thought that, if there was deemed authorisation, the pre-death procedure could go ahead to get the organs. Can we include something in the bill to explain to people that that would not necessarily happen? Can we do something about the language, for example, or do something to educate people—me included—about these things?

Harpreet Brrang: It needs to be made very clear to the public and family members that pre-death procedures could take place. At the moment, they might not be aware of what they mean. The first thing that people will say when you bring the issue up with them in the initial organ donation conversation is, "What are they?" As far as organ donation is concerned, people think that, once everything is switched off, the person is no longer there. That is probably the starting point for this particular conversation, because there is complete lack of understanding in this respect.

Emma Harper: I am itching to get in here, because I want to clarify what the pre-death procedures are. Are we talking about extra intravenous lines, arterial lines, central venous access or changing medication to improve renal function? Some meds might improve renal function, but they will also compromise liver function. Is that what we mean when we are talking about pre-death procedures? Are we talking about optimising organs in preparation for a donation process that we know we are moving forward with? Is this not about preparing for donation in the most optimal way instead of doing things without consent?

The Convener: Again, those are very good questions. Perhaps we will have other witnesses who will have a more medical perspective on that, but I see that Gillian Hollis wants to respond.

Gillian Hollis: It is exactly as Emma Harper has set out. It is based on the understanding that the person is about to become an organ donor and that, as a result, some procedures need to be carried out to ensure that the organs are working as efficiently as possible. These procedures would not be carried out if the person was not going to become an organ donor.

The Convener: Essentially, then, it is a clinical judgment. Alex Cole-Hamilton has a supplementary.

Alex Cole-Hamilton: I want to ask about the financial memorandum and capacity. If the bill is a success, it will lead to a greater number of organ transplants happening in this country than might otherwise be the case. Is there sufficient capacity in the bill, particularly the financial memorandum, to deal with the increase in workforce—both specialist nurses and surgical capacity—that will be required? Will we be ready for this if we pass the bill as it stands?

David McColgan: According to the Scottish Parliament information centre briefing, the Scottish Government has said that it is already funding to 2020 capacity levels. That target has been set, but it is not being met at the minute, so there will be funding to meet the extra positive impact that the bill will have.

The other point that I would make—and which came out in the previous member's bill—is about putting pounds and pence on a person's life. What we are talking about here, certainly as far as heart donations are concerned, is someone surviving or not surviving. The number of people in the UK who are waiting for a heart transplant has trebled in the last 10 years; in Scotland, it is 150 per cent higher that it was four years ago. We therefore need more transplants.

However, that will come with a cost. Somebody might have the exact figures, but when Kidney Research UK carried out an analysis of how much it cost to keep someone on dialysis instead of giving them a transplant, it found that the costs of giving them a transplant and bringing them off dialysis were significantly lower. The issue might come up again later, but if it does not, I can send the committee the figures.

The Scottish Government has made it clear that, with the 2020 target, money is there, but I would also point out that we are talking about people who are waiting for a second chance of life.

Alex Cole-Hamilton: Do not get me wrong—I am not concerned about the need to spend more money on this. I absolutely get the preventative agenda that you have described. I just want to be sure that we are ready with regard to the workforce and financial aspects and that we will be

able to absorb the additional demand that the bill will create.

Gillian Hollis: At one of our commissioning meetings, we looked at the finances of transplantation, and I learned a lesson: as a lung transplant recipient, I had been, in effect, funded by all the kidney transplants. We lucky heart and lung transplantees have benefited from the kidney transplant programme being so successful financially versus the cost of dialysis.

Let me leave finance to one side and talk about the practical implications. Our local Lothian organ donation committee is having quite a big discussion about theatre capacity. At the moment, most transplants are done in the evenings. Obviously, these procedures are unscheduled, and because they cannot be scheduled in the way that other elective surgery can be, they usually happen at night. I am aware of discussions happening locally about the pressure on theatres as a result of transplants. A number of resource issues need to be followed through. Again, it might be best to speak to the witnesses who know the area, but I think that if the numbers increase past the 2020 levels, the issue will have to be considered.

The Convener: I want to thank all our witnesses for their very helpful evidence to the committee. One or two questions were asked for which you had no immediate answers or on which you might need to reflect, and if you feel that there is something else that you want to say or draw to our attention, please feel free to make a post-appearance submission.

I suspend the meeting for five minutes to allow a changeover of panels.

11:14

Meeting suspended.

11:19

On resuming—

The Convener: I welcome to the committee Shaben Begum, director of the Scottish Independent Advocacy Alliance; Fiona Loud, policy director at Kidney Care UK; and Dr Gordon Macdonald, parliamentary officer for Scotland at Christian Action Research and Education. Thank you for coming to join us this morning.

I know that some of you sat in on at least some of the previous evidence session, so you will not be surprised that I will start with a general question. Do you believe that there is a need for the Human Tissue (Authorisation) (Scotland) Bill and that it will result in a marked difference in practice?

Fiona Loud (Kidney Care UK): Thank you for the invitation to speak today. Kidney Care UK is the national kidney patient support charity, and we welcome the opportunity to increase the number of transplants in Scotland, and across the whole country as a consequence of that.

People are dying every day while waiting for a transplant, and many of them are waiting for a kidney. We know that more can be done, and we absolutely believe that changing the rules so that it is presumed that a person will be a donor unless they have said otherwise in life is the right thing to do. However, it is not the only thing to do. It will work only if we take account of the views of the public, so we are very careful and clear about the need for education and promotion. A continuous and consistent message is needed across the country about what the bill aims to do, what it means and people's rights under it. We also believe that the change must be supported by the right capacity in the health service.

However, we certainly believe that the bill has the opportunity to transform lives, and it gives many kidney patients, who feel very strongly about this, some hope for a far better future and a life that is transformed through a transplant.

Shaben Begum (Scottish Independent Advocacy Alliance): We support the bill, but our main motivation for responding to the consultation was that we feel that the bill needs to be strengthened to consider the needs of people who have limited capacity or limitations on their ability to communicate and other marginalised groups. That is what we are interested in.

Dr Gordon Macdonald (Christian Action Research and Education): We would say that the answer to the question is no. What is needed is improvements to the administrative system around organ donation. The evidence from Spain suggests that what matters is not a legislative change that introduces presumed consent, but improvements to the administrative system and, in particular, specialist organ donation nurses. We suggest that it would be better to invest the money in that. The Nuffield Council on Bioethics found that, where specialist organ donation nurses exist, the donation rates increased from 27.5 per cent to 68.6 per cent. I think that that speaks for itself.

The Convener: We have met several specialist organ donation nurses. Is your point that there should be more of them rather than a change in the law?

Dr Macdonald: Yes.

The Convener: Thank you. It is clear that you all come from different perspectives. A key question that has arisen is that of the wishes of family members. There is no formal place for them under either the current legislation or the bill.

Should that change? Should the wishes of family members be written into the legislation in some way?

Dr Macdonald: It is very difficult for a clinician to go against the family's wishes at what is a particularly difficult and sensitive time. Whether they are written into the bill or not, I think that the practice will be, as seems to be the case in Wales, that clinicians will not go against the family's wishes. There is a dangerous precedent in allowing clinicians to override the family, particularly where there has been no opt-in on the part of the deceased. I am sure that clinicians are very conscious of that, but you will, obviously, have to speak to them.

We do not wish to see presumed consent being introduced in any case, but we would certainly want families to have a strong say as to whether it should happen and to be involved in the process. The evidence from Spain and other places seems to be that the key thing is dialogue and communication with families, rather than passing bits of legislation.

Shaben Begum: We need the bill to be really clear about rights. If it does not say anything about the rights of the family, that will be a potential barrier to its success. There needs to be that consideration. We need the bill to put in place safeguards for potential donors, family members and clinicians.

The previous panel gave evidence on the lack of clarity for clinicians and how it would be difficult for a clinician to go against the wishes of a family member. I agree that we should not put individual clinicians or teams in a position of having to be in dispute with family members. I carry a donor card, and if something happened to me and my family was in that situation, parts of my family would want to support my wishes and other family members would not. Good, robust legislation will need to take such nuances into consideration in order to safeguard everyone and protect my right to make that decision.

Fiona Loud: We believe that a soft opt-out is the right thing to introduce. That allows the family to present evidence as to why their loved one would not have wished to become a donor. We believe that, as we heard earlier, it is important to encourage people to have the conversation with family members all the time. If anyone takes the option to opt in, that is great. We would say to people, "Please let your family members know what your wishes are", but even if people do not take that option but are content to have their consent deemed, we would still like people to be encouraged to have that conversation. Having the conversation and knowing what your loved one's wishes are will make decisions much easier.

We should look at what has happened in Wales, with the right to a soft opt-out remaining, and what is proposed in England so that we can have some consistency. It is also important to train staff so that they understand the approach. If we look at Wales as an example, we can see what staff there learned about how to present the new rules and how they matured over time and became more confident about saying, "These are the rules and this is the law, but we would like to work with you as a family around the donation." I have heard family members from Wales speak about that and speak approvingly about the way in which deemed authorisation was introduced to them.

David Stewart: Good morning, panel. What assessment have you made of the strengths of the gift concept in the current legislation?

Fiona Loud: I will speak from the recipients' point of view first. There are about 464 kidney patients waiting or hoping for a transplant in this country at the moment. Any kidney patient who receives a transplant has the greatest respect for their donor and never forgets them. They remember the donor and speak of them with huge respect all the time. Recipients see the donation as a gift and will be forever grateful for the life transformation that the donor and their family have been able to grant them.

Turning to the point of view of donor families, we have spoken to many of them and they see the donation as their gift as well. The ones that we have spoken to are very proud to say that. I appreciate that they are only a selection, so I am presenting this as a story rather than as factual evidence, but they have also said that, provided that their wishes are still considered in the way that I described, with a soft opt-out, and their donations continue to be respected, spoken of in the highest possible terms and accepted as a vital part of what we are doing, they will be supportive and will still see it as a gift. They do not see that being taken away. I appreciate that not everybody feels that way, but that is the evidence that we have heard from the folk that we work with.

Shaben Begum: One of the strengths of the bill is that we have the concept of donation being a gift. It would be dangerous to squander that and introduce an element of compulsion or a notion that the state had certain rights over the bodies of individuals that would marginalise or sideline the wishes of the family. The packaging of the bill as people being able to provide a gift to other people in society is a really powerful message, and I think that the public will be open and amenable to that rather than to the idea that, if something happens to me, the state should be able to do whatever it likes with my body.

11:30

Dr Macdonald: The gift element is very important. As I am sure you are well aware, when the organ donation task force did its study in 2008, it found that the gift element was important not just to donors but to recipients.

There is a danger in moving away from the gift element. That is precisely the point that has just been made. If there is a perception that it is no longer a gift and the state is claiming a right, there is a danger that people will choose to opt out of the system, which seems to have happened in Wales. The number of people opting out has gone up to 182,000, or maybe 187,000—I cannot remember the exact figure—which is about 6 per cent of the Welsh population. In the other constituent parts of the UK, it is less than 1 per cent of the population. The effect is that, rather than 99 per cent of the population being potential donors—I have opted in to the donor register, but if I had not done so and something happened to me, my wife could still donate my organs—we have 94 per cent being potential donors in Wales.

We need to think about the potential negative consequences of moving away from the gift element towards—even if it does not exist in practice—the possible perception of a formal compulsion approach in law.

David Stewart: My next question relates to that. How important is simplicity of language in the bill?

Dr Macdonald: The bill and any associated documentation should be clear and honest. Part of the problem in Wales was that there was a fundamental misconception at the core of the debate, which was that the Spanish system was essentially a presumed consent system, whereas in practice it is an informed consent system because there is no opt-out register. A study in *The BMJ* by Professor Fabre and others including the leading Spanish clinician in the area argued that that was the case—that it was not in practice a deemed authorisation or presumed consent system; it was the system that we have in practice.

When the Health and Sport Committee previously considered the matter—I gave evidence on that occasion, too—some members went to Spain and spoke to the Spanish authorities. I would recommend that you do that as well.

Fiona Loud: There has been a great deal of debate about why Spain has been so successful in achieving world-leader status in organ donation and transplantation. Spain has done all the things that we would like to see. It has built its base in terms of capacity and training its staff as well as having a default that people are considered to be donors unless a different conversation goes on with the person and their family.

When the organ donation task force reported in 2008, it recommended a number of things based on the Spanish experience. It recommended the implementation of organ donation committees, trained staff and clinical leads, the embedding of specialist nurses in hospitals and a range of public education initiatives, but it did not recommend, as we know, that we should go with the presumed consent approach.

We are 10 years on and many of those things have been put in place, although there is still more to do on some of them. The one thing that we have not yet done is the thing that Spain and other successful countries such as Croatia have done, which is to change the law to go along with that. We believe that the combination of all those things is the right approach, and we hope that the Scottish Government is planning that.

Dr Macdonald: Croatia is an interesting case study. It now sits at the same rate as Spain, but what happened in Croatia was that it introduced presumed consent in legislation first, and it did not make any difference to the rates. It was only after Croatia did all the other things that the rates started to increase, which suggests that there is no direct link between the introduction of the legislation and the system and rates increasing. It is the other things that make the difference.

The Convener: Unless, I suppose, the change in legislation changed the context and made the other changes easier to deliver.

Dr Macdonald: Yes, but it was some years later. We can send you further evidence on that.

The Convener: That would be appreciated.

Fiona Loud: Changing the context and the national conversation alongside all those things is the thing that will make the difference, and that is why I quoted that country. It is all those things together. It is about changing the default and changing the support system alongside that.

Emma Harper: When we first started taking evidence, more than 80 per cent of Scots said they would donate their organs. I have had conversations with people who think that deemed authorisation is a way of allowing folk who just have not got around to putting their names on the organ donor register to donate. What is your response to that?

Dr Macdonald: It is the same as the point I made earlier, which is that we are talking about more than 99 per cent of potential donors in Scotland who have not opted out. I take your point about the 50 per cent of people who have opted in, which is very good compared with the rest of the UK. You quoted 80 per cent and a good 30 per cent of those people are realistically potential donors.

The key thing in relation to that will be the conversations that are had with the family around the time of death. That is where I come back to our point that the best thing to do, and the best way of using the resource well, is to invest in organ donation nurses. Certainly the UK Government's figures are £45 million start-up costs, £2 million a year to run the system, and then another £5 million or so every five years to run a publicity campaign. I do not know what the figures are for Scotland, but that money could certainly be better spent by investing in staff and in family communication.

Fiona Loud: Could I just comment on the point about eight out of 10 supporting organ donation, but only about half the population, for which Scotland is to be absolutely congratulated, being on the organ donor register? What we have is a group of up to 80 per cent of people who say that they would support donation and would be willing to donate who would be covered by the deemed authorisation bill. That is where there would be gains because there will always be people who will not wish to donate and having that right to opt out is incredibly important as part of the democratic work with the bill.

Emma Harper: Will the bill itself increase donation rates? That would be good, but if not, what areas will need to be invested in—you have mentioned some already—to increase donation among people who are on the organ donor register?

Shaben Begum: Your earlier point was a good illustration of the lack of awareness and understanding of a complicated area. It is so emotive. People think that if they are carrying a donor card that is the end of the story and their wishes will be safeguarded.

We need to have a bigger conversation within society. We do not talk about mortality. Lots of us do not have wills. Lots of people do not have advance statements, which is something that the Mental Health (Scotland) Act 2015 allows for. All sorts of things need to happen with infrastructure and finances, but we also need to have a conversation within society on a bigger level about what happens when we die and what we would like to see happen.

Dr Macdonald: It will be key to look at what has happened in Wales during the past four years or so. Everybody, including the Welsh Government, acknowledges that the evidence from Wales is inconclusive at the moment. However, certainly from looking at the stats, which I included in our submission, there is no clear link in terms of improving the figures.

In fact, what struck me when I looked at the NHSBT figures was that the deceased donor rate is increasing in all the other three jurisdictions in the UK, but in Wales it is not on a steadily increasing trajectory. It goes up and down each year, which is why it is quite difficult to just take a few years and make an assessment. More time needs to be given to see what happens in Wales before the Scottish Government and Scottish Parliament legislate in this area.

Fiona Loud: This is a national conversation and it is almost a once-in-a-lifetime opportunity for the whole country to raise our game and have that open national conversation that Shaben Begum just spoke so clearly about. The numbers of deceased donations that we are seeing are probably rising because we are having this national conversation in most of our countries about what is going to happen next and where we will go. However, we have to be careful—as one of the earlier witnesses said—because many people think the bill has already gone through. We have heard on the news that it has already happened, but it is still going through.

As a simple response to Emma Harper's original question about whether we think the numbers will go up over time, yes, we do think they will go up over time. However, we should be looking at the consent rate. In Wales, it is now something like 72 or 73 per cent. I think that it was at about 40 per cent or so when the scheme started, so there has been an enormous increase in consent rates. Family consent to donate rates are probably the best thing to look at because numbers will vary from year to year with what might be a relatively small number of donors, and one or two additional donors can make all the difference to the number of transplants. That is incredibly encouraging.

Brian Whittle: Good morning to the panel. Fiona Loud has partly answered the question that I was going to ask about evidence that we have heard many times that family consent is probably one of the major issues that has to be tackled within organ donation.

My question is specifically for Dr Macdonald. Do you acknowledge that Wales's success in raising the family consent rate is probably a more important indicator of success than the number of people who have opted out?

Dr Macdonald: We do not know what the reasons are. That is the key point. Is Wales's success to do with passing legislation on presumed consent, or is it to do with all the discussion that has been taking place in the media, including the information campaigns that have been funded, or is it to do with investment in specialist staff and improving communication with families? It is not clear. There needs to be some sort of bottoming out of what has caused Wales's success rather than assuming that it is just to do with the legislation.

You can certainly have a national conversation and invest in publicity campaigns without passing this legislation, and we would certainly support both those things.

Brian Whittle: Do you agree that the fact that we are having this discussion about the legislation is having an impact?

Dr Macdonald: It might be having an impact but the danger is that it is a negative impact. As we saw in Wales, a significant percentage of the population said, "I would not have minded in the past donating my organs, but if the Government is going to claim them then you can get lost". That is the real danger.

Brian Whittle: Your focus is very much on the opt-out there. Surely the outcome should be about the number of organ donations that are made rather than who is opting out.

Dr Macdonald: Indeed, but that is the point. The number of deceased organ donations has increased in other parts of the UK, but it does not seem to be increasing steadily in Wales. We need to get to the bottom of the reasons for that. The Welsh Government made all sorts of claims based on an academic study that there would be an increase of 25 to 30 per cent. We have to give it a bit longer to see how things develop, but the evidence to date suggests that that increase is not happening. That being the case, the danger is that you have an adverse impact rather than the positive impact that you were hoping to have, whereas if you did other things you could have that positive impact.

To be fair to the Scottish Government, that is what it has been doing. It has been putting a lot of effort into improving communication and putting extra resources into organ donation, which is why we have seen the rates, the number of donors and the number of people who are opting in rising steadily in Scotland.

11:45

Fiona Loud: I go back to what we can learn from Wales; I have no doubt that the committee will also take evidence from folk in Wales. To turn it around the other way, the startling increase in consent is a strong result of the impact of the work they have done there. It is also about learning from what they learnt in Wales about the importance of training staff—they knew about that but it was important to see it in action—and also of keeping families and family members informed on what the new rules are and what the law means. If we turn it around that way, far more members of the public in Wales know about organ donation and, as a consequence, more families have agreed to donate, through whichever route they have gone.

We would far rather have 80 per cent of the population be willing to donate, with the option for those who do not wish to donate, for whatever reason. I am not sure that we know enough about why people would have taken the option to opt out already, but that might be something to look at in the future. It is their right and there is no way that any of this is about a compulsion. It is about changing the default position so that Scotland is a country that accepts that organ donation is the natural thing to do with all the safeguards that I know we are discussing.

Keith Brown: I am fascinated by the evidence so far. I think that Fiona Loud referred to the person being content to have given their deemed consent; of course, the bill makes no provision for that. Shaben Begum, quite rightly, mentioned a scenario in which family members might have different views. Gordon Macdonald mentioned the fact that clinicians will have an obligation to listen to the families, although I would have thought that they would have an obligation to the person. The individual may or may not be a patient, as they could be deceased; I do not know what their legal standing would be.

It strikes me that, in such scenarios, the individual whose body it is could come third or fourth after the state, after the family, and potentially after the interest of the clinicians. Surely there must be some recognition of the rights of the individual—we have heard very little about that so far—especially if they have expressed a wish either to donate or not to donate.

Rather than asking a direct question, I am interested in hearing the witnesses' views on the rights of the individual whose body it is.

Shaben Begum: The individual's rights are paramount. The issue that I touched on earlier is that we cannot have a situation in which there is even a perception of compulsion in the bill.

It is interesting that you mentioned the state having rights. There could be a tricky situation of balancing the rights of different groups—that is always tricky—and the individual's rights need to be paramount. We cannot have a situation in which clinicians know that there are other patients waiting for organs—for a kidney or whatever—and that that is their motivation for carrying out a procedure. The wishes of the individual should be given the highest consideration.

Dr Macdonald: The heart of the debate is that the view of the individual who is the donor, if it has been expressed, should be respected. There is no question about that. Clearly, in some situations families have overruled that. That is a difficult scenario for clinical staff and more work needs to be done with families in order to reduce the risk of

that happening. The autonomy of people who are mentally competent and who have made a decision must be respected.

The issue that arises concerns the people who have not expressed a view one way or the other. The majority of those people would probably be content to donate, but some of them would not be content to donate; in those situations the state would be claiming a right that overrules that individual's right. Under the present system, in essence the family makes the decision. The family says, "They haven't made a decision, but we think that it would have been—". The family might be reflecting the deceased's view or it might be reflecting its own view, but in a sense that is the best that we can do in trying to get consent.

It is important philosophically for us to understand that the state does not have rights over us. The state has responsibilities to respect our rights—that is how human rights work. The duty is on the state to respect our rights and the rights are not given to us by the state but are inherent. Human rights legislation is about recognising the fact that we have inherent human rights.

When we get into a discussion that implies that the state somehow or other has rights over our bodies or other parts of our person—I am sure that that is not what Keith Brown intended—that is quite a dangerous philosophical step for us to take as a society. We need to be very careful not to be so focused on the pragmatism of trying to increase the number of donations, and on doing anything to achieve that, that we end up crossing a red line in the relationship between the state and the individual.

Fiona Loud: If an individual has expressed a wish to opt in or opt out, it is absolutely right that that should be honoured. We have worked with many patients who have said that they want to donate and that they do not want anyone to be able to override that. In practice, we know that the views of someone who has opted in are occasionally overridden because currently the family has to make the final decision. If the rules are to change, we must have a very careful and nuanced conversation about where that goes and what that means, in order to provide the patient's family with the opportunity to say, "That person has changed their mind and we know they have changed their mind," because people might change their minds.

We heard earlier from Gillian Hollis, who said she had changed her mind about how these things will work; others may do that, too. It is important that we provide that opportunity and that the safeguard is there, but that we honour the right of the individual when they have expressed their view. There are people who have not expressed a view, and for whom no other view is known, and that is the situation that the communication, the discussion and all those other things should be addressing. That is why it is very important that we are as clear as we possibly can be on what the new rules are, should the rules change.

Miles Briggs: I want to come back to the rights of families in a soft opt-out, because that is where the committee has focused some attention. Dr Macdonald, you were involved with a past bill; I think that this is the third bill on the subject that Parliament has considered. Has the current bill addressed some of the concerns? Have you seen some positive steps forward?

Dr Macdonald: I will need to rack my brains as to what the details were in the past bill. As I recall, there were concerns last time about the practical procedures and that was one of the main reasons why the committee rejected the bill.

I was interested to read in the SPICe briefing that the majority of committee members also rejected the bill because they were not convinced that it would make any difference to the numbers. I gave evidence as part of a private and informal consultation, at which two MSPs and a whole bunch of people were sitting round the table and it was very noticeable that everybody, from a variety of faith perspectives, had reservations. I do not know whether that had an impact on the committee's decision, given that only two MSPs were there. Somewhat ironically, there was more unanimity on this issue than there is on many issues between different people from different faith traditions.

Fiona Loud: I understood that the concern was to do with the practicalities and perhaps with the bill being a little bit overcomplex. This bill is more straightforward, and perhaps there are more things that we can discuss about making it as straightforward as possible. Some of the previous witnesses discussed that.

Shaben Begum: Quite often, legislation is not that accessible. Perhaps the challenge this time round is to make the bill as accessible as possible, and to engage the public in the consultation.

Brian Whittle: My question is on the idea that, if this legislation goes through, all of a sudden that will make a huge impact on the number of donors. Do you accept that a period of time will be required for the legislation to cascade down, and that there might be an increase in family consent that might lead to an increase in donation somewhere down the line? Are there examples from around the world in which such an increase has been seen over a period of time? I wonder whether there is a period of time that we should expect, or that we should at least be willing to work towards, that would help in that conversation.

Fiona Loud: Absolutely. There is not a magic wand that we can just wave and suddenly everything will be marvellous; if there was, we would probably have changed the system an awful long time ago.

Wales made the change three years ago, in December 2015, and it is still learning. Work is still being done there and I believe that the Welsh Government is looking at a period of up to 10 years before it does a final evaluation. In other countries that have been quoted, such as Spain and Croatia, again it has taken a number of years before the big changes have started to come into play.

Please correct me if I am wrong, but I think that the financial memorandum to the bill says that we should not expect increased capacity for transplantation until something like year 4. In other words, there is already a realisation that there will be a period of time before we get the uptake. It could take five to 10 years, because it is a whole lifetime change. It will also take time for the message to come through and be taken up by many of the younger generation—we know that they tend to sign up and opt in quite willingly—in the education system, as well as for those people to mature in their own lives. That is my suggestion, based on that evidence.

Dr Macdonald: The figures from Wales are interesting. In 2014-15, there were 128 deceased donor transplants. The legislation changed in 2015-16, as we heard, and the figure was 168. However, in 2016-17 the figure was 135 and for 2017-18 it was 139. We do not have data from Wales for a long period, but the limited data that we have does not suggest that the new system has made a spectacular difference. In fact, it might have reduced the figures compared with those for the 2015-16 period, but that is speculation because ultimately the biggest impact on the figures is the number of people who are dying in the appropriate circumstances. Again, there is sometimes a misconception that there will be a huge increase in the number of organs available, because only 1 per cent of deaths happen in the appropriate circumstances in which a donation can take place. That is the key factor in donor rates.

Alex Cole-Hamilton: Good morning, panel. Dr Macdonald, I know that you are not in favour of the bill, but I was struck by what you said about how we could improve organ donations; it was about dealing with administration. My question—particularly to Dr Macdonald and Shaben Begum—arises from what we do at the moment when we are consulting families and what we might do in the context of the bill. We met specialist nurses, who took us through the process, which revealed that something like 300 questions are put to grieving families at their most vulnerable time. That leads to many families overriding their family member's wishes and just saying, "Listen, I do not want to be part of this anymore."

Obviously, advocacy and getting people's views are important. However, could we use the bill to simplify that process so that people can express their views without having to go into intimate detail around their partner, or their son or daughter's lifestyle, and their suitability for transplant?

12:00

Shaben Begum: I was a little bit taken aback by the fact that there are 300 questions. I think that that will be a barrier if family members are in an emotional situation and cannot think that clearly, especially when there is a dispute.

I spoke about my family being in that scenario. I would completely support a reduction in the number of questions, and in their significance and intrusive nature. The intrusive nature of the questions was mentioned earlier.

Advocacy would work well in those situations. People could plan ahead and help others to think about what it would mean to opt in. It would also give the individual the strength and courage to have those conversations with their family members. Advocacy might help people who have capacity issues or communication difficulties, but I think that non-instructed advocacy would work well in those situations. We talked earlier about the pre-death situation. I might not be able to speak for myself, but a non-instructed advocate might be able to safeguard my wishes in that situation.

We were asked earlier whether the bill will make a difference straight away. I think that the bill is an example of a cultural shift that we need to have. It is not a panacea, and it will not sort everything out immediately. It is about changing our culture around these issues. Advocacy would play a key role in different situations for different people.

Dr Macdonald: If the problem is with the administrative system, legislation is unlikely to make a difference. The key thing that will make a difference is reviewing the administrative system.

I was surprised to hear the figure of 300 questions; I find that astonishing. If we are talking about 300 questions being asked in the current system—in which people have opted in—putting people into a situation of presumed consent, and putting relatives through such an onerous process, is likely to cause great angst if the relatives are not convinced of the person's wishes. That needs to be thought about.

Clearly, the system should be reviewed to see whether we can reduce the number of questions. You would need to talk to clinicians to see how

that could be done. If the system is so burdensome, I would caution against creating a situation in which relatives, at a very difficult time, are put in the position of having to answer 300 questions when they are not convinced in the first place that the deceased or the dying person would have wanted it.

The Convener: In fact, up to 350 questions might be asked. However, some of those questions are asked during particular lines of questioning in response to an earlier answer, so by no means everyone is answering 300 questions.

Fiona Loud: That is a helpful clarification.

At the moment, the specialist nurses will be asking a whole range of questions, which will be necessary. I cannot comment on the questions themselves, because they will be to do with safeguarding and that side of things. In England, I believe that rather than writing the questions, or the need to ask them, into the law the plan is for them to be covered by the code of practice, so that it can be consulted on separately through the Human Tissue Authority. In order to keep the bill as simple as possible, I suggest that that side of things could be covered in the code of practice; it would still be absolutely and correctly dealt with, but it would perhaps not come up as a potential barrier to the law being introduced.

That is one suggestion, alongside the fact that there are already a range of questions that will be asked very sensitively by well-trained specialist nurses. We have heard from families who find those questions distressing, but the families that we have heard from have also said that they appreciate why the questions are being asked, because if they are in favour of donation they want it to go through. Keeping the process simple and perhaps removing it from the law but including it in the code of practice would be a different approach.

Dr Macdonald: If there are good clinical safety reasons why questions need to be asked, presumably those questions will still need to be asked even under a system of presumed consent. That is the key point that I am trying to make.

The Convener: It is a fair point.

David Torrance: In Wales, deemed consent applies to people aged 18 and over. In Scotland, deemed authorisation would apply to potential donors aged 16 and over. Do you agree with 16 being the age at which deemed authorisation would apply?

Dr Macdonald: We do not agree in principle anyway, but the point that you make is valid and needs to be looked into because, if legislation was different on either side of the border, there is a danger that there could be some sort of judicial review of a particular case.

Fiona Loud: The messaging would have to be very careful if the age threshold was different here. I also think that the implications of there being a difference should be considered further, with regard to whether it would be better to be harmonious with the rest of the country or to stay with the proposed age threshold.

Shaben Begum: We support 16 being the age at which deemed authorisation would apply, but I point out that there are a lot of anomalies in different pieces of legislation with regard to when someone is considered to be a child. For example, the age of consent is 16, but young people are considered to be adults at other ages in other legislation. This would be another such anomaly.

David Torrance: As we have heard, the 16-and-under age group is sometimes a difficult one to engage with—it is especially difficult to get them to engage with their parents. How can we provide sufficient opportunity for young people in that age group to express their wishes?

Fiona Loud: I am going to say education, education, education. In terms of the school curriculum, I know that there are some excellent tools already out there that are aimed at secondary schools and particularly at people of 15 and 16—not just the slightly older younger people, if that makes sense.

It is also important to encourage people to have those conversations with their families, because, as we often say, children are the change makers. If we give children a good amount of education on the issues—not in terms of what they must or must not do, but as part of the education that they receive on health and being a part of society—we can ensure that they receive unbiased information about what it might mean and can be encouraged to talk it through with their families.

Shaben Begum: The dealings that I have personally and professionally with young people suggest to me that some of them are much more enlightened and open-minded than lots of older people or adults. I completely support Fiona Loud's point about education and awareness raising, but I think that there would be examples of young people changing the minds of their family members and parents as well.

Fiona Loud: I agree. That is why I made the comment about children as change makers.

Dr Macdonald: I signed up to the organ donor register when I was renewing my car tax—I was offered the option as part of the process and I thought, "Well, okay". It would seem to me that there are opportunities in the system to engage young people—for example, when people sit their

driving test or apply for a driving licence, although maybe not when they apply for their Young Scot card, as that involves people of a younger age. Those opportunities could be taken, and there could even be opportunities to allow people who are younger than 16 to express a view without necessarily making a commitment.

Fiona Loud: Social media are, obviously, incredibly important to young people, most of whom will be world experts in them before they get anywhere near 16. It is important to use that approach.

Sandra White: Good morning. I will ask this panel the question that I asked the previous panel about pre-death procedures—the name is bad enough anyway. Concerns about the procedures have been raised with us. Basically, legislation for the procedures is being considered, but the detail of those procedures is not yet in place. Other people have raised concerns about pre-death procedures going ahead under deemed authorisation. What are your thoughts on the pre-death procedures? Shaben Begum talked about advocacy, and perhaps that should be included before someone gets to that stage.

Shaben Begum: In relation to advocacy, the constituency that we are interested in in this context would be people who have limited capacity with regard to communication, and people who are covered by the 2015 act, because I would not want to see the legislation discriminating against a group of people and saying that they cannot donate their organs.

Capacity is not a black and white issue. Someone who can make decisions about certain aspects of their life might be deemed not to be able to do so in relation to other aspects, such as their finances. We have safeguards such as guardianship and power of attorney, and those are the places where I think that there needs to be consideration with regard to organ donation. That would be part of a national conversation around donation.

The situations that we are talking about are not scheduled—they cannot be planned for. In those situations, non-instructed advocacy might play a crucial role in ensuring that the rights and wishes of the person are respected. Earlier, we raised the issue of balancing the rights of the family, the state and the individual, and advocacy plays a crucial role in redressing the inherent imbalances of power and dynamics within relationships. The issue that we are discussing would be a prime example of that. There needs to be somebody there who is independent and does not have any agenda within the situation but is there to safeguard an individual's wishes and reinforce their rights and ensure that their rights and wishes are being listened to appropriately.

Other people within that dynamic and within that situation will have their own agendas and their own wishes, but especially when an individual does not have a physical voice, it is important that there is a mechanism for ensuring that their views are heard.

Dr Macdonald: One can understand why pre-death procedures would take place. As we heard earlier, the idea is to maximise the likelihood of the success of a donation. Where I think there might be a concern would be if there was any impact upon the care of a person who would otherwise not be dying, for example—we cited the UK Supreme Court's recent judgment in relation to people with severe neurological conditions and so on. You also raised in the earlier session the issue of people whose brain might still be functioning even though their heart has stopped beating. Certainly, I have heard people express concerns about organ donation on that basis in the past. Those issues need to be carefully considered.

Fiona Loud: The concept of an advocate could be helpful in some situations, as Shaben Begum said. It is important to be clear and transparent, and we should look to do that, but we must also be sensitive to the fact that not all families want to know all the details, by any means. They want to know what is going to happen, how long it is going to take and so on, but they do not necessarily want to know everything. They have a right to be supported through the donation process by a well-trained member of staff.

12:15

Emma Harper: Sandra White brought up pre-death procedures, and Shaben Begum mentioned incapacity. Does the bill adequately cover people who might have communication difficulties or incapacity difficulties, and should the language in the bill be widened to cover that?

Shaben Begum: Our feeling was that it does not adequately cover those groups of people, and that it needs to be strengthened.

Alex Cole-Hamilton: I have a question about capacity and the financial memorandum. I am conscious that none of you are clinicians, but you may have a view. From your experience of working in the transplant world—I direct this part of the question to Fiona Loud in particular—do you think that there is going to be sufficient capacity built in after the legislation is passed to meet any increased demand, and are we making enough money available to that end in terms of workforce planning?

Fiona Loud: I welcome the fact that the financial memorandum contains an estimate of when numbers of staff need to go up to support the anticipated increase in transplantation—I

believe that it says that that will be in year 4. I think that that is the right thing to do, but we need to watch very carefully and evaluate how things are working as we go along, because we do not want families who wish to donate being put off by delays in the system. Recently, I asked about this issue in Wales, following some work that had been done there. They did not feel that the issue had been a problem, but they were aware that it might become one.

With a different hat on, I am a chair of an organ donation committee at my local hospital, and I am quite aware of the need to be able to make theatre space available in order to go forward with a donation from a family. From my experience there and in other hospitals, I know that chief executives of trusts are very supportive of that and understand the issue. However, we need to be cognisant of the fact that, as I said earlier, these circumstances are not always planned, and, often, the donations will take place in the middle of the night. It is important to ensure that appropriately trained surgical staff are available, as well as an adequate space. We need to have put some plans in place in that regard and we must watch very carefully how things develop to ensure that we can continue to do the right thing.

Shaben Begum: In addition to the points that Fiona Loud has made, there needs to be proper training around capacity. There is a danger that we think only about the capacity of the person who is going to be the organ donor, but there needs to be proper consideration of the capacity of the family who might be making a decision and who might all disagree with or support the decision and so on. There needs to be proper training for staff around that as well.

Dr Macdonald: I come back to my earlier point. I cannot comment on whether the Government's planning in relation to the financial aspects of the legislation is accurate or sufficient, but we think that it would be better to use the resource that has been committed to this in other ways.

The Convener: I thank all of our witnesses once again. The session has been helpful. As I said to the previous panel, if you have any questions for us or further information that would be helpful to the committee, feel free to get in touch.

12:19

Meeting continued in private until 12:52.

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